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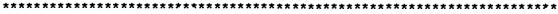
#### **ABSTRACT**

Part of a volume which explores current issues in service delivery to infants and toddlers with handicapping conditions, this chapter discusses the nature of parent involvement in early childhood special education. Acceptance of the basic axiom of parent involvement needs to be accompanied by an understanding of individual differences in ramily styles and flexibility in the design of intervention methods. Strategies for involving parents in the process of parent-mediated instruction should also be individualized, and the needs of all family members taken into consideration. Four models of family functioning are described (family systems theory, ABCX, family life cycle, and transactional); common variables such as resources and parental expectancies are identified; and the impact of selected variables on the level and quality of family involvement is described. The Individualized Family Service Plan (IFSP) as an extension of the concept of the individualized education program is also discussed. Assessment of the child, the family, and the dynamics of parent-child interaction are described as providing important information for the IFSP planning conference. A sample family goal worksheet is presented, and a list of references concludes the chapter. (JW)

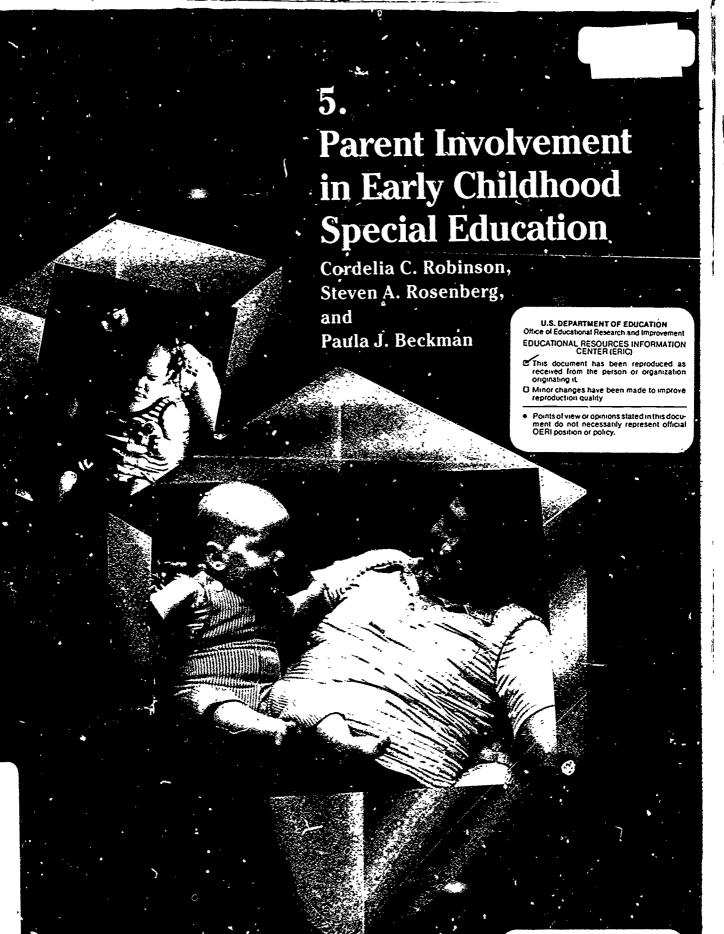
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In this chapter we will discuss the nature of parent involvement in early childhood special education. Within that general theme we will look at the rationale for parent involvement, ways in which parents have been involved in programs, and the requirements for parent and family involvement as identified in the new legislation, Public Law 99-457, the Education of the Handicapped Act Amendments of 1986. We will identify our assumptions about meaningful parent involvement. Next we will discuss models that have been proposed for the study of families. Within these models, we will identify variables that have been demonstrated to relate to the manner and/or success of parent involvement. We will provide some specific illustrations as to how these variables have been demonstrated to affect parent involvement and from those examples draw implications for developing individualized family service plans as required under P.L. 99-457. Finally, we will discuss implications of these examples for evaluating parent involvement within the context of individualized family service plans.

# RATIONALE FOR PARENT INVOLVEMENT

Parent involvement has become an almost universal characteristic.

Parents were expected to play an instrumental role in day-to-day activities.

Emphasis upon parent involvement has become an almost universal characteristic of early intervention programs for handicapped infants and toddlers. However, when programs involving direct intervention with handicapped infants began to gain momentum in the early 1970s, the nature of parent involvement was markedly different from what we see in intervention programs today. Parents were expected to play an instrumental role in the day-to-day intervention activities with their children, and several arguments were offered to justify this. Initially, professionals working in the field of early intervention involved parents in order to extend the impact of intervention. Three reasons have been cited by professionals and parents advocating for legislation that requires parent involvement in intervention programs:

- Since the child spends the bulk of his or her time with parents, the more knowledgeable they are about child development strategies and activities, the greater the impact of intervention.
- Parent/child interaction and its relationship to child development was used as a rationale for involving parents in their children's educational programs.
- 3. Lack of personnel available to work with young handicapped infants makes parent involvement necessary.

# ISSUES IN THE DESIGN OF PARENT INVOLVEMENT

Goals of parent involvement need to be clarified.

As the number of early intervention programs has increased over the past 10 to 15 years there has been a corresponding increase in the number of strategies used to involve parents in their children's educational programs. In order to evaluate these various strategies, a number of issues must be considered. First, the goals of parent involvement need to be clarified. Currently, parent involvement assumes a partnership between parents and professionals. Therefore, in programs the meaning of equal partnership must be established and how equal status on the



team for parents and professionals can be achieved in light of their probable differences. These include differences in their knowledge of disabling conditions and in their respective roles. Finally, when methods for involving parents are designed, individual differences in both family constellation and cultural style need to be accommodated.

## ASSUMPTIONS REGARDING PARENT INVOLVEMENT

☐ In identifying variables that may affect the level and nature of parent participation in early intervention programs, we are making a number of assumptions about parent participation. First, we assume that parent participation is a necessary component of programming for infants and young children. We assume this because young children spend he majority of their time in the family context and need to be looked at in this context. In addition to this logical argument, there is a multitude of written materials and personal testimony from parents and professionals working in the field of early intervention regarding the essential nature of parent involvement. Second, we assume that the primary reason for involving parents is the impact of such involvement upon child development. We also assume that intervention strategies must be flexible and negotiated with families in order to accommodate differences in family styles and in the manner and intensity of parent involvement. Finally, we assume that parents must assist in designing and implementing the service system in which they will participate.

We assume parent participation is a necessary component.

Parents must assist in designing and implementing the service system.

#### CHANGES IN THE NATURE OF PARENT INVOLVEMENT

☐ We, as well as others in the field of intervention with young disabled children, have noted how parent involvement has changed over the past two decades (Foster, Berger, & McLean, 1981; Rosenberg, 1977; Wiegerink, Hocutt, Posante-Loro, & Bristol, 1980). A number of factors have influenced those changes, including an emphasis upon parentmediated instruction, program reports indicating variability of level of family participation in parent-mediated intervention, changing family patterns, and introduction of family systems theory. Historically, professional efforts directed toward helping families with disabled children focused upon parents and children separately. Efforts directed toward parents used counseling techniques and focused on acceptance of and adjustment to the child with a disability. Professional efforts to enhance child development were committed to the direct treatment of the child. But changes occurred because of the growing compensatory education movement directed toward families with children considered to be at developmental risk due to conditions of poverty. This movement promoted an emphasis upon direct involvement of parents in instruction of their children.

Historically, efforts focused on parents and children separately.

#### PARENT-MEDIATED INSTRUCTION

☐ There is now increasingly widespread acceptance of the importance of having parents directly involved in the education of their young children



Aspects of the family influence the capacity to nurture its children.

Needs of all family members must be addressed.

who have developmental problems. As the practice of involving parents became common, and as efforts to teach parents intervention techniques increased, so did reports that the strategies of parent-mediated intervention did not work in all cases. One explanation offered for this lack of uniform success was the lack of individualized strategies for involving parents in the process of parent-mediated instruction.

Aspects of the family, the characteristics of its members, and the total

Aspects of the family, the characteristics of its members, and the total context in which it exists greatly influence its capacity to nurture its children. At times, professional efforts are most profitably directed toward providing supports that enable parents to exercise their caretaking skills effectively. Interventions that focus on the family, parents, or social and economic context are necessary when the conditions of life make it impossible for parents to perform their child-rearing functions adequately. Under these circumstance, no direct form of intervention aimed solely at the child is likely to have substantial impact. Instead, the needs of all family members must be addressed.

#### CHANGING FAMILY PATTERNS

Parent-mediated instruction was derived from the compensatory education model.

This changing pattern included increased number of single-parent households.

□ Foster et al. (1981) have pointed out that parent-mediated instruction for families with disabled children was derived primarily from the compensatory education model. The model assumed that the deficiencies of low-income children in school-related tasks derived from deficiencies in their home environments. While this deficit model was reasonably congruent in the early First Chance projects that served mildly handicapped children, as more multiply and severely handicapped children came to be served in early intervention projects, the original assumptions and techniques of parent involvement were found to need examination.

Another changing pattern that affected the assumptions and strategies of parent-mediated intervention was the larger context of the American family. This changing pattern included the increased number of single-parent households in which the custodial parent is the mother, the concomitant feminization of poverty, and in the remaining two-parent households, the greater likelihood of both parents working outside the home (Bristol, 1987; Foster et al., 1981). In this regard, Foster and associates pointed out that most strategies of parent-mediated intervention assume a nonworking parent who has time to integrate the recommended interventions into the daily routine.

As more and more intervention programs were developed with professionals and parents involved, there were more opportunities to see variations in strategies and, of course, variations in outcome. Also, there was an increase in the number of people calling for research to help understand variations in outcomes. Most often these people suggested that concepts used in clinical work with families would be helpful in developing a better understanding of variations in outcomes and subsequently in individualizing intervention strategies so as to produce more uniformly successful outcomes (Dunst, Cooper, & Bolick, in press; Foster et al., 1981; Rosenberg, 1977; Turnbull, Summers, & Brotherson, 1986). In the next part of this chapter, we will examine theories of family functioning and propose a system for classifying variables that appear to



be common across theories of family functioning and are likely to affect the success of intervention strategies.

#### MODELS OF FAMILY FUNCTIONING

☐ Historically, theorists interested in the study of families have proposed several different models from which to view family functioning. Most of these models were not originally developed as a means for studying families of handicapped children. However, in recent years a number of investigators have acknowledged the usefulness of these theoretical approaches as a way to understand the impact of a handicapped child on the family. In this section, several of the most prominent approaches will be briefly reviewed, variables that are common across the models will be identified, and implications of these models for interventionists will be described.

Theorists have proposed different models.

#### Family Systems Theory

☐ The family systems approach has been receiving increasing attention by investigators studying families of handicapped children. This approach is based on the general systems theory as described by Von Bertalanffy (1968). Essentially, this theory asserts that all living systems are composed of a number of parts that are interdependent in the sense that influences associated with one part of the system are likely to affect other parts. Interaction of the parts creates features of the entire system that are not present in any of the parts individually. More recently, family systems theory applications have been extended to families of handicapped children (Dunst, et al., in press; Fewell, 1986; Turnbull et al., 1986). The family systems theory has been an important contribution to our understanding of family functioning. Investigators have recognized that in order to understand family functioning, they cannot simply consider individual members in isolation. Rather, relationships among members and the ecological context in which the families exist must be considered as well (Bronfenbrenner, Avgar, & Henderson, 1977).

General systems theory asserts that all living systems are composed of a number of parts.

#### ABCX Model

☐ Another model of the impact of events upon families is the ABCX model, originally developed by Hill (1949). Hill's model has been the basis of a longstanding interest in the general literature regarding family relations. Essentially, the ABCX model provides a framework in which a family's reactions to stressful events may be considered.

Briefly, the ABCX model includes four major components. The stressor event (A) interacts with the family's resources (B) and the family's definition of the event (C) to determine the extent to which the event becomes a crisis for the family (X). Several decades of research on stressful events have been based on Hill's model, and components of the model have been elaborated and given considerable attention in the literature. However, only in recent years has the ABCX model been applied to families of handicapped children (Wikler, 1986).

The model is important because the components allow investigators to understand the considerable variability with which families react to the

The ABCX model provides a framework in which reactions to stressful events may be considered.



Birth of a handicapped child is considered a nonnormative stressor. birth of a handicapped child. Thus, when applied to families of handicapped children, the ABCX model may help us explain why some adjust exceedingly well, while for others the experience is devastating. By looking at variability in family reactions to stress, it may be possible to devise individualized strategies to assist families who are having difficulty. For example, the A factor, the stressor event, has been as a life event or transition capable of producing a change in the family social system (McCubbin & Patterson, 1983). Hill distinguished normative stressors from those that are nonnormative. The birth of a handicapped child is generally considered a nonnormative stressor.

In Hill's model, the family's response is likely to be determined by the

In Hill's model, the family's response is likely to be determined by the family's crisis-meeting resources (the B factor). The B factor includes such variables as individual characteristics of each family member, social support, family interaction patterns, and other similar variables. Indeed, in recent years researchers have found that the availability of social support mediates the extent to which families report increased stress following the birth of a handicapped child (Beckman, Pokorni, Maza, & Balzer-Martin, 1986; Bristol, 1979; Bristol, Gallagher, & Schopler, 1987; Crnic, Friedrich, & Greenberg, 1983; Gallagher, Beckman, & Cross, 1983). Thus, there seems to be growing evidence to document the importance of Hill's B factor, that is, family resources, in understanding variability among families in their adjustment to a child who is handicapped.

The family's perception is an important factor. Hill's C factor, the family's perception of the event, has received less direct attention in the literature but is a potentially important factor. Although few studies of stress acknowledge the importance of the individual's perception of the event in producing stress, many measures of family stress essentially measure the respondent's perception of the effect of various life events. In order to fully understand the effect of this component of Hill's model, more research is needed to distinguish it from the other factors in the model and to look at differences in perception of the importance of various events among different family members. For example, do mothers and fathers perceive the same things as stressful? How do differences in their perceptions influence family functioning in regard to the resources brought to bear or the coping strategies that are used?

#### Family Life Cycle Model

Families are believed to go through a life cycle demarcated by key stages.

□ A third approach which has frequently been used to view families is a family development or family life cycle model (Duvall, 1957; Mederer & Hill, 1983). Essentially, family development theory deals with the issue of family change over time. Families are believed to go through a life cycle demarcated by key stages. Stages are established based on three criteria: (a) a change in family size, (b) the developmental stage of the oldest child, and (c) the work status of the breadwinner. Eight stages were originally proposed by Duvall; however, over the years, the number of stages has been modified by different investigators. Duvall's original stages include (a) the establishment stage, (b) first parenthood, (c) family with preschoolers, (d) family with school-age child, (e) family with adolescents, (f) family as a launching center, (g) family in middle years, and (h) family in retirement.

Functions of the family and the roles played by various family members are thought to change based on the family's developmental stage. It is in



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the transition from one stage of the cycle to the next that the most potential for stress exists. Turnbull et al. (1986) have incorporated the notion of family life cycles into their thinking about the effects of handicapped children on families. They point out that, in addition to normal transitions, families of handicapped children are likely to experience additional stress associated with transitions. Since stages are grounded in the age of the oldest child, families of handicapped children may not experience transitions when they are expected, or both the stages and the transitions may be unusually long.

Several considerations are important when attempting to apply the family development model to families of handicapped children. First, the nature of the family has changed dramatically in recent years. There is a growing number of "blended" families, children who participate in multiple households, and families headed by single parents. For these families, clear stages are often difficult to identify and there may be multiple transitions. Second, the life cycle approach assumes that the impact of a crisis will be greater when a family is in transition from one stage to the next than when a family is within a stage period. While transitions may tend to be difficult, it is important not to ignore the rather significant changes that can occur within a particular stage. This is especially true for families of high-risk or handicapped infants. During infancy, there are numerous milestones that may not be achieved when they are expected. Failure to achieve milestones may be a continuing source of stress during the first few years of life. For high-risk infants hospitalized for long periods of time, the weeks of hospitalization may be highly stressful. Thus, while the life cycle approach to families is useful, focusing on the stress of transitions may cause professionals to overlook important sources of stress that occur for families within stages.

#### Transactional Model

☐ The fourth model we will consider is the transactional model. The transactional model was orginally developed by Sameroff & Chandler (1975) to account for the difficulty professionals often have in predicting developmental outcome for high-risk infants. They argue that neither biological nor environmental factors alone are sufficient predictors of outcome for high-risk infants. Although it is more useful to view outcome for high-risk infants in terms of the interaction between biological and environmental events, even an interactional model is insufficient to account for variations in outcome. Sameroff & Chandler urged the adoption of a transactional approach, which acknowledges the interaction between environmental and biological contributors to development, but argues that these factors after the impact of each upon the other over time. Thus, biological and environmental variables interact at time one to produce changes in each other. These changed biological and environmental variables then interact at time two, and so on. The term transactions refers to the dynamic process of change over time that can be used to explain development.

Beckman (1983, 1984; Beckman-Bell, 1981) has applied this approach to explain stress in families. Characteristics of the child, the family, and the ecological context in which the family functions interact over time to produce changes in one another. For example, if an infant is irritable, difficult to console, and irregular in sleep-wake patterns, these characteristics may influence the family in many ways. The sleep of other family

Families of handicapped children are likely to experience additional stress associated with transitions.

There is a growing number of "blended" families.

Failure to achieve milestones may be a continuing source of stress.

Transaction refers to dynamic process of change over time.



members may be disturbed, ultimately resulting in chronic fatigue, and interaction patterns between the parents and the infant may be disrupted. Over time, these events may continue to influence the family. The marital relationship may suffer, there may be in a stime spent with nondisabled siblings and other family members, and the child's development may be adversely affected.

#### **COMMON VARIABLES**

Although the theoretical models described herein are useful in understanding family functioning, none were specifically formulated as a way to understand the issues faced by families of handicapped children, nor do they always have direct implications for interventionists. As a result, interventionists may not always find these theories useful for developing interventions for families. In the remainder of this section, we will illustrate how the theoretical models can be used as a basis for designing interventions.

To apply family theory to the study of families with disabled infants, it is useful to identify variables that are common across theoretical models. For purposes of discussion in this chapter, we have placed variables in one of three categories: input variables, mediating variables, and output variables. Input variables are those factors that are identifiable at the point the child and family are first seen and that may influence family functioning. Input variables are the "givens" of family life—variables that families bring with them and that are not readily changed. Inputs include the stressors that impinge on the family, its income, the education and intellectual attainments of its members, their health and disability characteristics, and their stage in the life cycle.

Mediating variables are those factors that are likely to influence a family's ability to adjust to changes and cope with crisis. Mediating variables are characteristics of the family that are more readily changed. They influence the impact of input on the family's ability to contribute to the well-being and development of its members. Examples include available resources (e.g., time, money, programs available); social support (e.g., neighbors, friends, extended family members who can provide social support); internal coping strategies (e.g., psychological strategies used by individual members or the family to alter their perception of the situation, such as identifying aspects of the situation that can be changed); cohesiveness and consensus; adaptability; patterns of interaction among individual members; and the ability of members to communicate needs and feelings.

Output variables include child outcomes (e.g., measures of child development, behavior, health) and measures of family outcomes (e.g., level of stress, cohesiveness among family members, physical and emotional health of family members). Finally, it is important to remember that families change over time, and what was initially to be considered an "output variable" may later become an "input" to the system.

# ILLUSTRATIONS OF THE IMPACT OF SELECTED VARIABLES

☐ Many variables influence parental involvement in early education programs. In assessing and serving individual families, it is helpful to

Interventionists may not always find these theories useful.

It is useful to identify variables common across models.

Input variables are not readily changed.

Mediating variables are more readily changed.

Output variables include measures of child and family outcomes.



3

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understand the events and circumstances that hinder parent involvement with their children's programs. This information allows us to determine which supports are most likely to help them become satisfied participants in their children's education.

#### Impact of Resources

☐ Resources can refer to both emotional and physical factors. A family must have sufficient control of quantities of food, shelter, and manpower to maintain itself and its disabled member. In addition, the family must have emotional support in order to continue functioning under emotionally trying circumstances. Bronfenbrenner (1975) pointed out that inadequate nutrition and health care, poor housing, lack of education, limited income, and the necessity for long or unusual working hours all constitute components of an environment that can sap parents of time and energy. Additional data arguing that adequate resources are required if families are to be able to support an intervention can be found in the work of Patterson, Cobb, and Ray (1973), who observed that mothers lacking financial and manpower resources had difficulty learning child management techniques.

Personal and social resources must also be considered. Parental depression (McLean, 1976) or psychopathology, chronic illness, limited intellectual abilities (Kaminer, Jedrysek, & Soles, 1981; Rosenberg & McTate, 1982), and adverse family relationships are individual and family characteristics that can also limit parental willingness and capacity to become involved in program activities. It is well documented that a retarded child makes taxing emotional and physical demands on family members (Farber, 1960; Holt, 1958; Mercer, 1966), as do a child's physical disabilities (Mercer, 1966; Walker, Thomas, & Russell, 1971), oppositional behaviors (Berkowitz & Graziano, 1972), and chronic illness (Crain, Sussman, & Weil, 1966).

Exhaustion, a side-effect of keeping disabled children at home (Holt, 1958), is associated with the institutionalization of such children (Mercer, 1966). Lonsdale (1978) reported that parents of disabled children experience increases in tension, illness, and/or ability to work. This unfortunate reaction may be expected to adversely affect parents' involvement in programs for their disabled children.

#### Intervention Focused on Resources

☐ Families with severely handicapped children often require substantial manpower and financial resources. To deal with this resource problem, Wolfensberger (1969) argued that such families should be eligible for housekeeping assistance, day care, and income subsidy so that they may continue to maintain the child in their home. The family's social network may prove to be another source of emotional and material assistance. Supportive interventions that reduce parental distress should have a positive effect on children. For example, children have an improved rate of recovery from surgery when efforts are made to reduce the anxiety of their mothers (Skipper & Leonard, 1968).

#### Impact of Expectancies and Goals

☐ Parents' personal characteristics also influence their willingness and ability to become involved in early intervention programs. In particular,

Resources refer to both emotional and physical factors.

Personal and social resources must be considered.

Interventions that reduce parental distress have a positive effect on children.



Gratifications of infant care can be reduced when the child is severely handicapped.

parents' expectancies and goals for their children affect their involvement in program activities (Rosenberg, 1977). Their aspirations for their child are generally perceived as thwarted when the child is diagnosed as handicapped. To a great extent, this is the result of society's devaluation of disabled people and the consequent devaluation of parenting disabled children. Because of this, the parents begin to question many of the goals that are commonly held for children. In addition, many of the gratifications of infant care, such as the observation of rapid development, expectations of future growth and development, and social pride, can be greatly reduced when a child is severely handicapped. It is not surprising that some parents are ambivalent about committing themselves to what they may perceive as a lifetime of unrewarding and futile effort.

Parental goals and values also affect participation in program activities. Parents who can value their children regardless of their attainments will have an easier time investing in the education and development of their young children than will parents who are highly concerned with the social status of their families and children. In this connection, Rosenberg (1977) found that, among mothers of handicapped infants, those who placed greater emphasis on economic goals and social status were judged to be less involved in their children's educational programs.

# Intervention in Expectancies and Goals

☐ In cases where parents are reluctant to involve themselves in intervention programs, short-term contracting may provide a reduction of parental anxiety and shift parental perception from long-term commitment, which they may find everwhelming, to more acceptable periods of days or weeks. Where needed, succeeding contracts may be lengthened and, in time, eliminated altogether. The use of time-limited agreements allows parents to control their involvement and permits them a trial period in which to familiarize themselves with their program responsibilities. This procedure is common in behavioral therapy (Knox, 1971). Other procedures may also be used in generating parental involvement; naturally, the particular strategies used will vary for different families.

#### Impact of Consensus

☐ Family members must reach some agreements about the nature of their goals, the allocation of tasks, and the coordination of activities, including child care and therapy. Where there is a lack of consensus among parents regarding the execution of household and therapeutic activities, or where parents and professionals differ over home program goals, the treatment of the child will suffer. For example, parents who differ intensely over issues related to child care will be unable to agree on activities related to their child's program. Patterson, Cobb, and Ray (1973) have observed that marital discord is associated with failure to learn child-rearing skills.

Conflict between retarded children and members of their families or with schools is thought to be associated with the institutionalization of retarded persons (Mercer, 1966). When there is a lack of consensus between spouses, and the father is unfamiliar with the rationale for the procedures his wife uses, Radin (1972) suggested that the father be involved in the program in ways that are consistent with his role in the family. She found that involved tathers were more likely to reach

Time-limited agreements allow parents to control their involvement.

Marital discord is associated with failure to learn child rearing skills.



agreement with their wives and project staff on goals and procedures than were fathers who remain uninvolved. Beyond this, the capacity of parents to resolve their differences can be enhanced by teaching them ways to negotiate and seek compromise solutions (Weiss, Hops, & Patterson, 1973).

#### Intervention on Consensus

☐ Where consensus between parents and program staff breaks down, negotiation procedures can be employed to reduce conflicts. Differences over goals and procedures can be pinpointed, the alternatives considered, and the advantages and disadvantages of the various possibilities discussed by parents and staff. Ultimately, a compromise solution can be designed and, where needed, the agreement recorded as a written contract.

## Summary

☐ We have provided a few illustrations of how some of the variables typically looked at in models of family functioning have been studied in families with a disabled member. It is apparent that the concepts called for in P.L. 99-457 to be included in the design of individual family service plans (IFSPs) are consistent with both clinical and research findings in the field of early childhood special education.

Conc ts are consistent with clinical and research findings.

# THE INDIVIDUALIZED FAMILY SERVICE PLAN

© P.L. 99-457, passed in the fall of 1986, extends the concept of the individualized education program to include a statement of the family's strengths and needs in relation to the child in the form of an IFSP. The intent of this legislation is for the IFSP to become the basis for work with disabled children and their families. Regulations already stipulate that the IFSP must contain the following:

- 1. Description of the child's present level of developmental functioning.
- 2. Statement of the family strengths and needs that are relevant to facilitating child growth and development.
- 3. Statement of anticipated outcomes as a result of enhancing family functioning.
- 4. Description of the services needed by child and family.
- 5. Dates of initiation and conclusion of services.
- 6. Identification of the case manager.
- 7. Description of the steps for transition of a child from present program to next program.

The family-oriented approach mandated by this legislation addresses children's needs within the context of their family's needs. The literature cited in this chapter points to the need for services for young children that are individualized not just for the child, but for the family as well. However, systems (especially systems that serve a large number of people) are notorious for becoming less flexible over time in what occurs in the implementation of policies and procedures. As professionals across



They must be aware of the complexity of the mission and need for flexibility.

disciplines continue to work in early childhood special education and embark upon implementation of P.L. 99-457, they must be aware of the complexity of the mission and the need for flexibility in the design of guidelines for IFSPs.

# INDIVIDUALIZING THE FAMILY SERVICE PLAN

☐ In 1982, Turnbull and Turnbull pointed out that despite program variations, early childhood special education programs shared the following implicit assumptions or beliefs regarding parent involvement in programs:

- 1. The parents (and the child) should be part of the process from which they are so often removed—a belief in shared decision making.
- 2. Parent participation should increase the appropriatenesss of the educational services—a belief in parent involvement as a means of ensuring that schools satisfy their legal obligations to children.
- Parents should receive counseling and training to prepare them to be part of the education of their child at home—a belief in the role of parent as teacher (p. 116).

Turnbull and Turnbull's point was that we need to examine our assumptions regarding parent involvement and become open to the fact that not all parents want or have the resources to strive for these idealized roles of decision maker, advocate, and teacher. Just as the kinds of educational activities and the manner of their presentation should be adjusted to the characteristics of each individual child, so too should programs attempt to accommodate the characteristics of families served. Effective support of family involvement requires adjusting the nature and level of involvement of the program to best fit the needs of children and their parents.

Programs should attempt to accommodate characteristics of families.

## FAMILY-FOCUSED APPROACHES

Over the past several years, groups involved with the delivery of services to infants have cited the need for consideration of a number of issues if our approaches are to be family-focused (Bailey et al., 1986; Olson, Bostick, Jones, & Tate, 1987). While these approaches have varied in specific elements, they share a common problem-solving approach. Recommended problem-solving steps include (a) designating a case coordinator; (b) assessing child and family needs and strengths; (c) reviewing assessment findings with the family; (d) holding a staff conference to discuss any specific child or family strengths, resources, or deterrents that need to be highlighted before meeting with the family to select goals; (e) holding an IFSP meeting; (f) implementing services, and (g) monitoring services and revising the IFSP as needed.

This problem-solving format provides professionals and family members with information on which to base the cycle of steps, which includes planning, intervention, and revision. When this process is used, goals and accompanying objectives can correspond with the family's changing needs and circumstances. In addition, the parents have opportunities to determine their own goals and comment on evaluation findings.

Goals and objectives can correspond with changing needs.



The evaluation and planning process must be coordinated; this is generally done by a professional who is able to maintain contact with family and other team members. It is the coordinator's responsibility to see that everyone at the IFSP meeting has an opportunity to be heard. The coordinator is also responsible for checking with the team, including the parents, to determine how successfully the IFSP is being implemented.

#### ASSESSMENT OF CHILDREN AND FAMILIES

☐ Approaches to the assessment of handicapped children and their families vary considerably across programs (e.g., Bailey et al, 1986; Olson et al., 1987; Rosenberg, Robinson, & McTate, 1981; Turnbull & Turnbull, 1986). For the purposes of the IFSP, assessment of the child should determine current level of development in cognitive, motor, communication, psycho-social and self-help skills. As with IEPs, these findings should be based upon data derived from nondiscriminatory measures and should reflect a multidisciplinary approach to assessment.

Parent-child interaction is an important area for assessment when serving young children who have handicapping conditions. For young children, interactions with their parents are an enormously important source of learning and mutual enjoyment. These interactions are frequently made difficult by handicapping conditions. Responsivity and sensitivity, along with other parent characteristics, have become common elements in intervention strategies that emphasize parents' ability to read and respond to their children's communicative cues. Such an emphasis is appropriate since there is evidence that infants' handicaps can alter their interactive capacities in ways that impair their ability to contribute to enjoyable exchanges with their parents. For example, they may respond slowly to their parents or use atypical modes for communicating their interest. As a result, interactions may be less enjoyable and may occur less frequently. Parents may be more directive toward their handicapped infants, and they may have difficulty recognizing and responding to their infants' communications and expressions of interest. It is easy to see that these responses by parents can result in decreases in child involvement in activities; in turn, this may further complicate parental efforts to find mutually satisfying patterns of interaction.

Fortunately, parents and their handicapped babies can be helped to establish mutually satisfying interactions that foster child growth. Several characteristics of enjoyable parent-infant interactions promote child development. Parents should be responsive to their children's interests and moods when interacting with them; wherever possible, children shoul' be encouraged to initiate exchanges and select materials. Active responding by children should be sought rather than the passive responding associated with extensive use of prompting or physical guidance and there should be a match between children's developmental capacities and the developmental level of the tasks and communications presented to them. Feedback regarding performance on curricular activities should be informative and positive in affect. Parents can be assessed on these dimensions. The information obtained during assessment can be used to give them specific instructions and explanations for

Findings should be based on nondiscriminatory measures and reflect a multidisciplinary approach.

Parents should be responsive to their children's interests and moods.



making the most of interactions with their children (Rosenberg & Robinson, in press).

The third area for assessment is the family—its inputs, mediators, and outputs. Assessment of a family's input characteristics provides information about the composition of the family. A knowledge of mediators reveals the procedures the family uses to resolve conflict, the coping abilties of its members, and the extent to which members agree with each other on important issues, as well as the availability of resources and social supports. Output information addresses the family's current level of functioning.

Input information begins with the family's composition and structure.

Input information begins with the family's composition and structure. Composition includes family members, their ages, educational attainments, and employment status. Also included is information about the health of family members and the caretaking needs of the children. Boundary permeability or cohesion of the family structure may be evaluated first. A family's external boundaries maintain the distinction between the family and the rest of the world and influence the level of cohesion among members. Boundaries within the family define the subsystems that comprise the family and regulate interaction by determining who is included in making decisions affecting family life and the extent to which individuals affect one another by their actions and outcomes (Minuchin, 1974). The boundaries of the family can be assessed by observing the family's openness to new ideas and materials from the outside world.

Family boundaries are also assessed by interview and self-report questions.

Boundary maintenance and permeability is also indicated by the extent to which families seek to participate in decisions that affect family members and regulate the flow of people and materials into their household. The state of the family's boundaries is also assessed by interview and self-report questions that ask (a) the extent to which they feel that their roles as parents have been taken over by people from outside the family, and (b) the number of agencies with which the family is involved. Internal family boundaries are assessed by determining which members are involved in decision making (Rosenberg, 1977). In instances in which members are inappropriately involved in or excluded from decision making, or, for example, where decision making has been turned over to outsiders, this would be noted as a problem. Strategies for decision making would be addressed with the family.

Family's material resources must be assessed.

A family must have adequate material and social resources to maintain itself and its members. In addition, the family must have the emotional strengths and problem-solving skills needed to permit its continued functioning under stressful circumstances. Each family's material resources must be assessed by determining its income, the state of its housing, and access to transportation. In this connection we also consider parents' level of education, employment history, and job-related skills. Psychological strengths of family members are assessed by history and emotional and intellectual abilities are evaluated through clients' self-reports and worker observations. The availability of support from extended family and friends is also assessed (Peterson, 1981; Rosenberg, 1977).

Mediating variables include consensus among members.

Mediating variables influence the processes by which families are able to use their resources and the efforts of their members to produce a functioning household. These include consensus or the extent of agreement among members regarding goals, priorities, and the division

of labor; information about how family members relate to one another; and information about coping skills of family members.

A knowledge of consensus among family members is useful because families must reach some stable arrangements with regard to their goals, the allocation of tasks, and the coordination of family activities, particularly child-related tasks, if they are to be effective caregivers. Where there is a lack of consensus among parents and professionals over home program goals, the care and treatment of the child may be expected to suffer. Consensus between spouses and between professionals can be assessed by self-reports (e.g., Olson et al., 1987; Rosenberg, 1977) as well as by less formal discussions.

Coping is often mentioned as an important determinant of a family's health. A family's capacity to cope is determined by the effectiveness of the strategies used by the family as a whole and by individual members to continue orderly functioning despite changing circumstances. One useful inventory of coping strategies is F-COPES (McCubbin, Olson, & Larsen, 1981), a self-report measure that asks respondents to indicate the extent to which they use certain coping strategies. Family level outcomes may be assessed in terms of the extent to which the family meets its member's fundamental needs for the maintenance of life and health as well as for less basic necessities such as love and an environment that is supportive of personal development.

Several measures of task allocation in the family are also available (Olson et al., 1987; Gallagher, Scharfman, & Bristol, 1984). These are self-report instruments that ask respondents to indicate the extent to which parents participate in tasks required for the maintenance of the family.

After the assessment phase is completed, the family meets with the assessment team to review the findings. Parents are given information about their child's developmental status. The family evaluation results are also reviewed; the extent to which the family believes these results accurately reflect their present status is determined. This step is particularly useful where the evaluation relies mainly on self-report measures that do not involve conversation between the family and professionals. In addition, preliminary discussions of child and family needs and goals occur at this point.

A staffing is held after the family and child assessment data have been collected. Staff representing ail disciplines involved with the child and family attend and review findings. A family goal worksheet such as that included in Figure 1 can be used to structure this meeting.

An IFSP planning conference with the family is then held to identify and finalize both child educational goals and family goals; family members and professionals select goals regarding the family's and the child's needs and identify strategies for achieving those goals. Professionals and family members should discuss methods for overcoming obstacles that interfere with completion of a desired activity or goal. A plan is developed for reevaluating the goal or associated objectives if necessary. A commitment is written itemizing goals, describing how and when goals will be evaluated for completion, and setting up a time line. This family goals worksheet should also list the person responsible for the goal and the resources available to assist in the completion of the goal.

Once developed, a family goal worksheet (Figure 1) based on family plans usually does not remain static. After being implemented, an intervention plan must be reviewed where necessary and modified so that it reflects changes in the needs and circumstances of the family and

Coping is an important determinant of a family's health.

The family meets with the assessment team to review findings.

An IFSP conference is held to identify child and family goals.

An intervention plan must be reviewed and modified.



Figure 1. Family Goal Worksheet.

**FAMILY GOAL WORKSHEET** 

needed to cover

services to infant

AGE\_ Family/Child Needs Family Resources Goal Competing Needs or Recommended Deterrents to Methods Success Motor development Coping strategy. Physical therapy twice Lack of transportation. Physical therapy needs Family high on use of weekly. Father has varied should be offered in work schedule. the home, or obtain external support. assistance from Family Responsibility Four other young extended family and Checklist shows Mom children in the home. friends to bring child in doing 90% of to appointments. household tasks. Dad Mom has heavy time commitment to family indicates his desire to and other children. share more responsibility. Family is rigid and enmeshed on FACES and scales. Large group of extended family and friends who are willing to offer support. Work with Mom to Father's pay is Coping strategies: Increasing skill in Financial resources

accessing local and

obtain SSI or Medicaid

state resources to

support.

FAMILY NAME \_\_\_

Note: From Olson, Bostick, Jones, & Tate (1987). Reprinted with permission.

Family high on use of

external support. Mom

is assertive in her

agencies.

unpaid.

communication with

Family is living on a minimal budget. Hospital bills for infant's delivery as yet

its members. Information about family members' responses to intervention provides the feedback with which each plan's appropriateness is evaluated. This feedback also guides modification of the plan. Plans are most frequently modified by changing treatment goal priorities as additional goals are added when unanticipated problems arise. Second plans also must change when intervention strategies are found to be ineffective.

variable, thereby

Medicaid.

influencing status on

Father is hesitant to

take state assistance.

obtain SSI coverage

Meet with Dad to

discuss financial

needs of infant.

for infant.

CHILD NAME \_\_\_

## CONCLUSION

☐ In our conceptual model of how individualization of the family service plan can occur, we indicate that the characteristics of the child, family,



and program interact and that program development needs to be responsive to those characteristics. In that regard, we want to highlight one dimension of that responsibility for flexibility and adaptation. In addition to being responsive to the child's educational and habilitative needs and the family's resources, both material and supportive, for meeting those needs, programs should set a tone of negotiability in the development of the IFSP. The framework of the negotiation cannot be based upon those assumptions regarding parent participation that Turnbull and Turnbull (1982) pointed out were implicit in early childhood special education programming rhetoric. Rather, the negotiation of the IFSP should be entered into without preconceived solutions.

We have many strategies and approaches, and it is our responsibility to design our programs so that all of our strategies are used in appropriate situations. This is the same basic philosophy that underlies the development of individualized education programs (IEPs). Yet we find ourselves attending IEP meetings for which the outcomes are, in large measure, prepared in advance. The defense frequently offered for such advance preparation is that parents are not really prepared to write goals and strategies. Of course, in many cases they are not, at least initially. Frequently, the atmosphere at such meetings is so intimidating, albeit unintentionally, that parents have to be seasoned veterans to feel they can contribute. The same danger of lack of parent participation exists in the construction of an IFSP. The program and staff are responsible for preventing an atmosphere that opposes professionals with the "answers" to parents who feel that they have nothing to contribute.

Programs should set a tone of negotiability in the development of the IFSP.

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